Patients requesting prophylactic mastectomies overestimate their breast cancer risk

March 25 2010

Barcelona, Spain: Women who have been diagnosed with breast cancer believe the risk of the disease occurring in their unaffected breast is as much as ten times higher than it actually is. As a result, they are choosing to have prophylactic mastectomies based on a false perception of increased risk, according to new research.

However, Mr Ajay Sahu MD, a consultant breast surgeon at the Frenchay Hospital (Bristol, UK), will tell the seventh European Breast Cancer Conference (EBCC7) today (Thursday) that if the women are given time to think and counselling to help them understand their actual risk, they often decide against a prophylactic mastectomy. The results of his research could lead to a reduction in the numbers of prophylactic mastectomies, as well as saving women from unnecessary side-effects caused by the treatment.

Mr Sahu reached his conclusions after conducting a study of 27 consecutive patients, aged between 31-65, who were diagnosed with breast cancer between April 2007 and October 2009, and who were having surgery on one breast but were requesting that the other breast should be removed too.

"I set out to do this study because the incidence of contralateral prophylactic mastectomy was increasing in my unit," he said. "I felt that the time of diagnosis was a moment of increased stress and not the right

time to make such a decision. There are two aspects to this study. One is the patients' perception of risk at the time of diagnosis and the other is whether this perception can be influenced by deferring the decision-making process."

There is no evidence that women who have a single, small breast tumour or who are at low to moderate risk of developing a further breast cancer, gain any survival benefit from a mastectomy or a contralateral prophylactic mastectomy (removal of the other, unaffected breast). "Yet these procedures are increasingly being accepted as patient choice and offered by clinicians who do not address the possibility of an inaccurate perception of risk as the reason behind their patient's request," said Mr Sahu. "The incidence of contralateral prophylactic mastectomy has almost doubled in recent times without any evidence of survival benefit and the reasons for this need to be addressed and alternative strategies considered."

The reasons given by the 27 Frenchay patients for requesting a contralateral prophylactic mastectomy included: young age, but without a family history (three patients), lobular cancers (seven patients), family history, which was deemed low risk by the surgeon (12 patients), bad experience of treatment outcome among family or friends (four patients), and a desire to avoid radiotherapy (one patient). All the patients thought that they would not live longer than five years, and all overestimated their risk of contralateral breast cancer by a factor of five to ten.

Mr Sahu asked about the patients' perception of risk and the reason behind a request for prophylactic mastectomy at the time of diagnosis and then the operation was deferred. Breast care nurses counselled the patients at the time of diagnosis and when the post-operative results and plans for adjuvant treatment were discussed. The patients received adjuvant chemotherapy and/or radiotherapy and were followed up at six

months by the breast care nurses and at 12 months by the surgeon. At the end of twelve months those who still requested prophylactic surgery were offered the operation.

However, at the end of the 12 months all the patients were less anxious about their risk. Four patients (three with a family history and one with lobular cancer) were happy with the actual risk but still asked for prophylactic surgery. The remaining 23 patients were pleased to have had the opportunity to rethink and chose not to have prophylactic surgery.

Mr Sahu said that the 12 months delay before any prophylactic surgery did not make the women more anxious. "The 'cooling off period' actually helped to reduce anxiety (although we did not explore this specifically) and helped the women to be comfortable with the decision they made in the end. Patients were happy with the alternative strategy to prophylactic surgery: in other words, they had an understanding of actual risk of bilateral breast cancer, an understanding that the risk can be reduced by treatment and surveillance by annual mammography, and that no survival benefit is conferred by the operation.

"Although this study is small and should be treated with caution at this early stage, the important message is that the patient's choice may be based on inaccurate overestimation of risk at the time of diagnosis, and, given time, they may not have the same risk perception later on. Healthcare professionals should be aware of this and offer a 'cooling off' period to facilitate appropriate decision-making. The study is continuing and when we have recruited more patients we hope to be able to make more definite recommendations."

Mr Sahu is continuing his research by studying the psychological aspects of patients' decision-making processes.

Provided by ECCO-the European CanCer Organisation